



ARKANSAS CENTRAL CANCER REGISTRY and NATIONAL CANCER SURVEILLANCE

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National Program of Cancer Registries

ACCR and National Cancer Surveillance

- Status of national cancer surveillance system
- Status of ACCR
- CCR data in comprehensive cancer control
- Availability of national comparison data
- Next steps and summary

Current National Cancer Surveillance Partners



History of Cancer Registration in the United States

- **1921 – Bone Sarcoma Registry**
- **1930s – 1st hospital based registries**
- **1930s – Connecticut Cancer Registry**
- **1971 – SEER Program**
- **1987 – NAACCR**
- **1990 – National Cancer Data Base**
- **1992 – CDC-NPCR (Cancer Registries Amendment Act)**

Cancer Surveillance Prior to NPCR

- No nationwide, population-based cancer surveillance in the U.S.
- Approximately 40 states had a central registry
- Data items/records not standardized
- In most states, no data available for planning/evaluation of cancer control activities

SEER Surveillance Epidemiology & End Results

- Covers ~26% of the US population
- Collects population based data on incidence, treatment, and survival
- Used to estimate cancer incidence in US

Cancer Registries Amendment Act

- Passed by Congress October 24, 1992
- Authorized CDC to establish NPCR
- Set requirements for central registries funded by NPCR

Reportable Cancer

Public Law 102-515

"each form of invasive cancer with the exception of basal cell and squamous cell carcinoma of the skin and each form of in situ cancer except for carcinoma in situ of the cervix uteri"

Benign Brain Tumor Cancer Registries Amendment Act

- Legislation passed October, 2002
 - Amendment to the Public Health Service Act authorizing NPCR (PL 102-515) to provide for the collection of data on benign brain-related tumors
 - Implementation: Cases diagnosed on or after 1/1/2004

Cancer Registries Amendment Act authorized CDC to:

- Work with states to develop model laws & regs
- Set national standards for completeness, timeliness, and quality
- Provide training on Central Registry operations
- Standardize a minimum set of data items
- Provide funds to states and territories to enhance or plan and implement registries

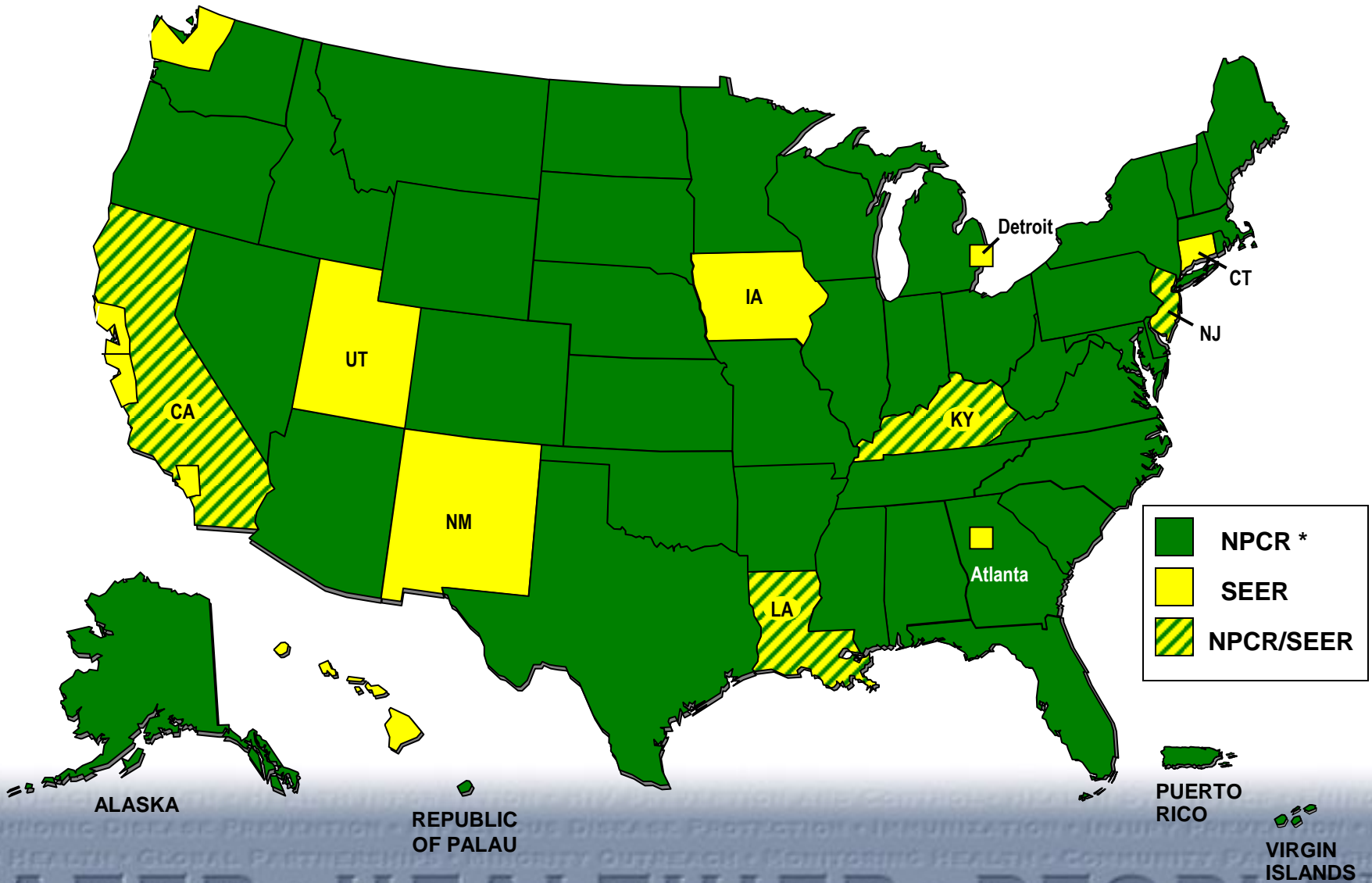
NPCR Program Requirements

- State\territory wide, population-based registry
- Statewide legislation/regulations
- Compliance with standards
- Uniform data elements, uniform format
- Statewide annual report

NPCR Legislation and Regulations

- Authorizing legislation supports existence of central registries
- State regulations:
 - Comprehensive reporting
 - Access to records
 - Reporting of uniform data
 - Protection of confidentiality
 - Access to data by researchers
 - Authorization to conduct research
 - Protection from liability

National Cancer Surveillance

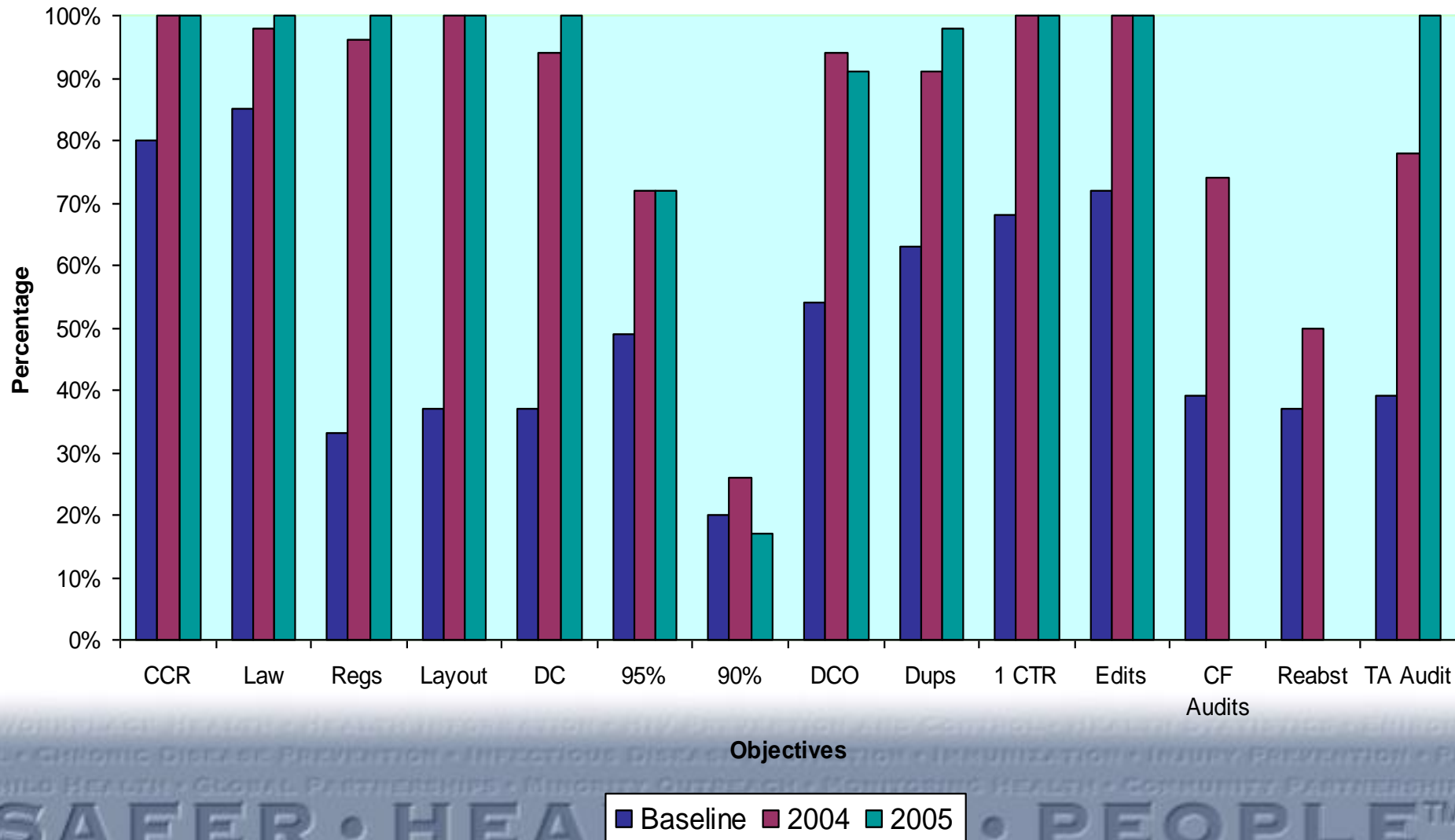


*National Program of Cancer Registries (CDC)

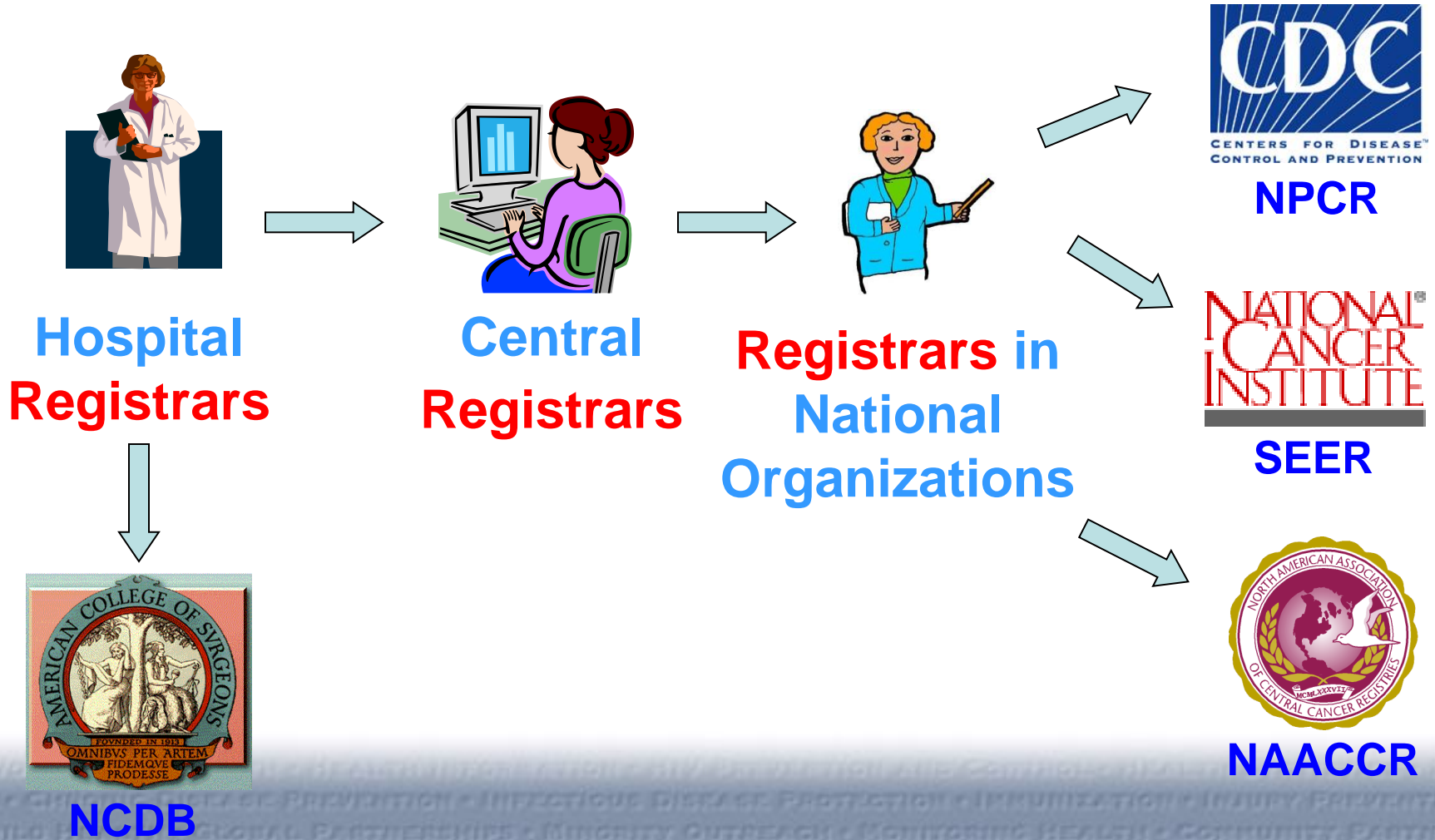
†Surveillance, Epidemiology, and End Results Program (NCI)

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NPCR Progress in Meeting Program Objectives



Registrar's Role in US Cancer Surveillance



NCDB

NAACCR

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Ideal NPCR Central Cancer Registry

- Population-based
- 100% case ascertainment
- Timely case reporting
- High quality data
- Timely analysis and reports

NPCR Program Standards for Completeness

- 90% of unduplicated, expected, malignant cases within 12 months
- 95% of unduplicated, expected, malignant cases within 24 months
- $\leq 3\%$ Death Certificate Only cases within 24 months
- $\leq 1/1,000$ duplicates in database within 24 months

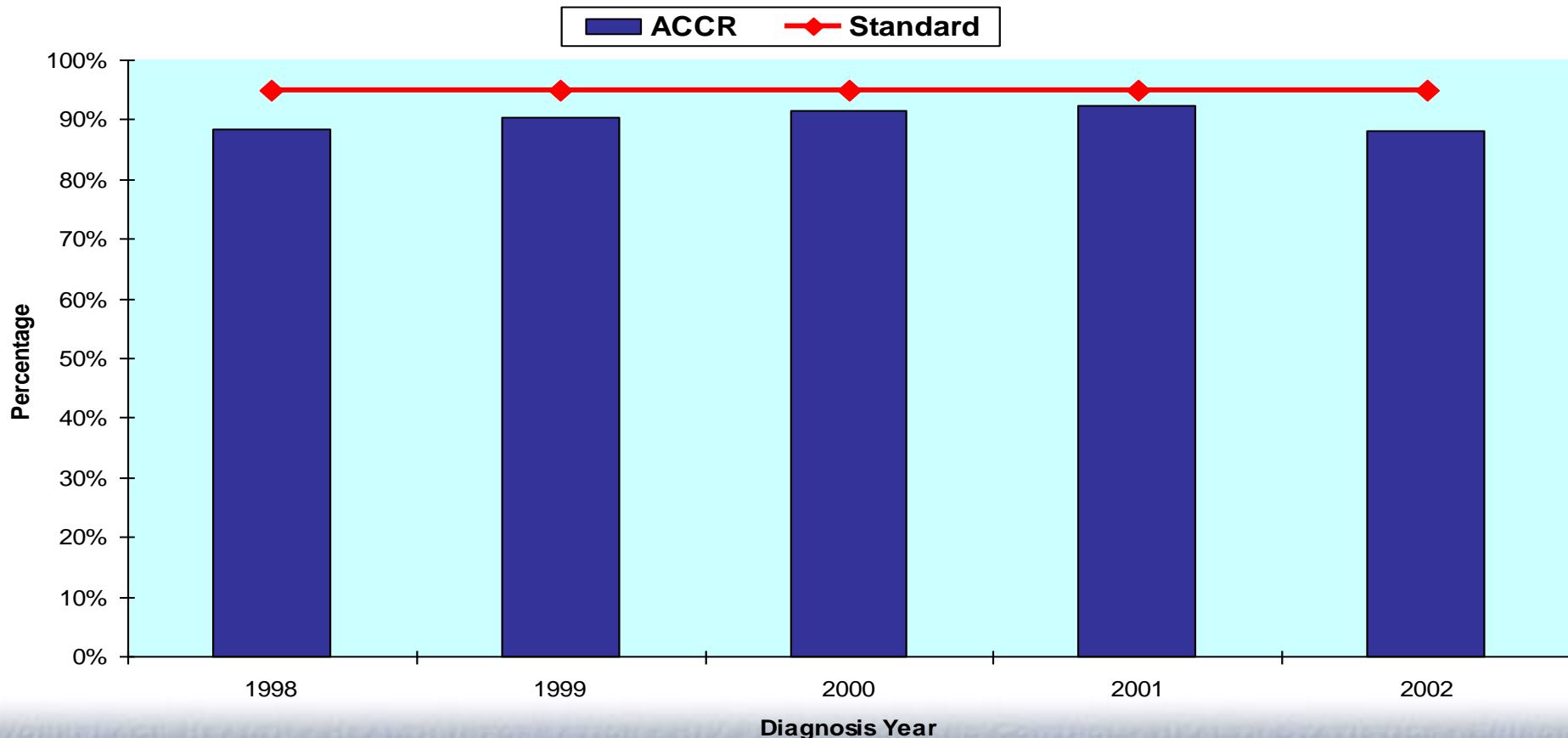
Standards for Completeness (continued)

- NPCR endorses the NAACCR method of calculating case completeness as described in Cancer Incidence in North America, (1988-93) and as adopted by the Data Evaluation and Publication Committee, September 12, 1996.

NPCR Program Standards for Timeliness

- 90% of unduplicated, expected, malignant cases within 12 months
- 95% of unduplicated, expected, malignant cases within 24 months
- $\leq 3\%$ Death Certificate Only cases within 24 months
- $\leq 1/1,000$ duplicates in database within 24 months

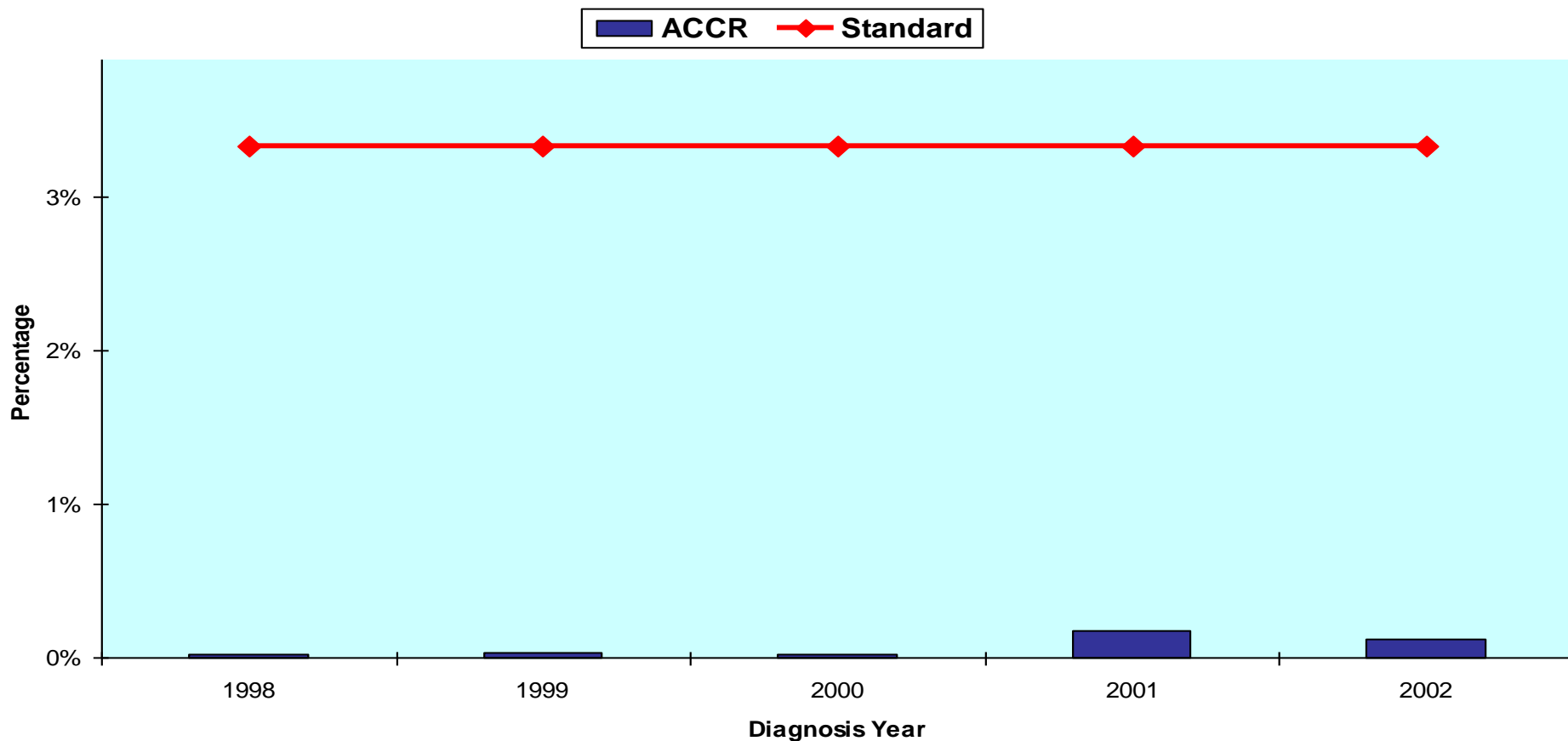
ACCR Completeness of Case Ascertainment



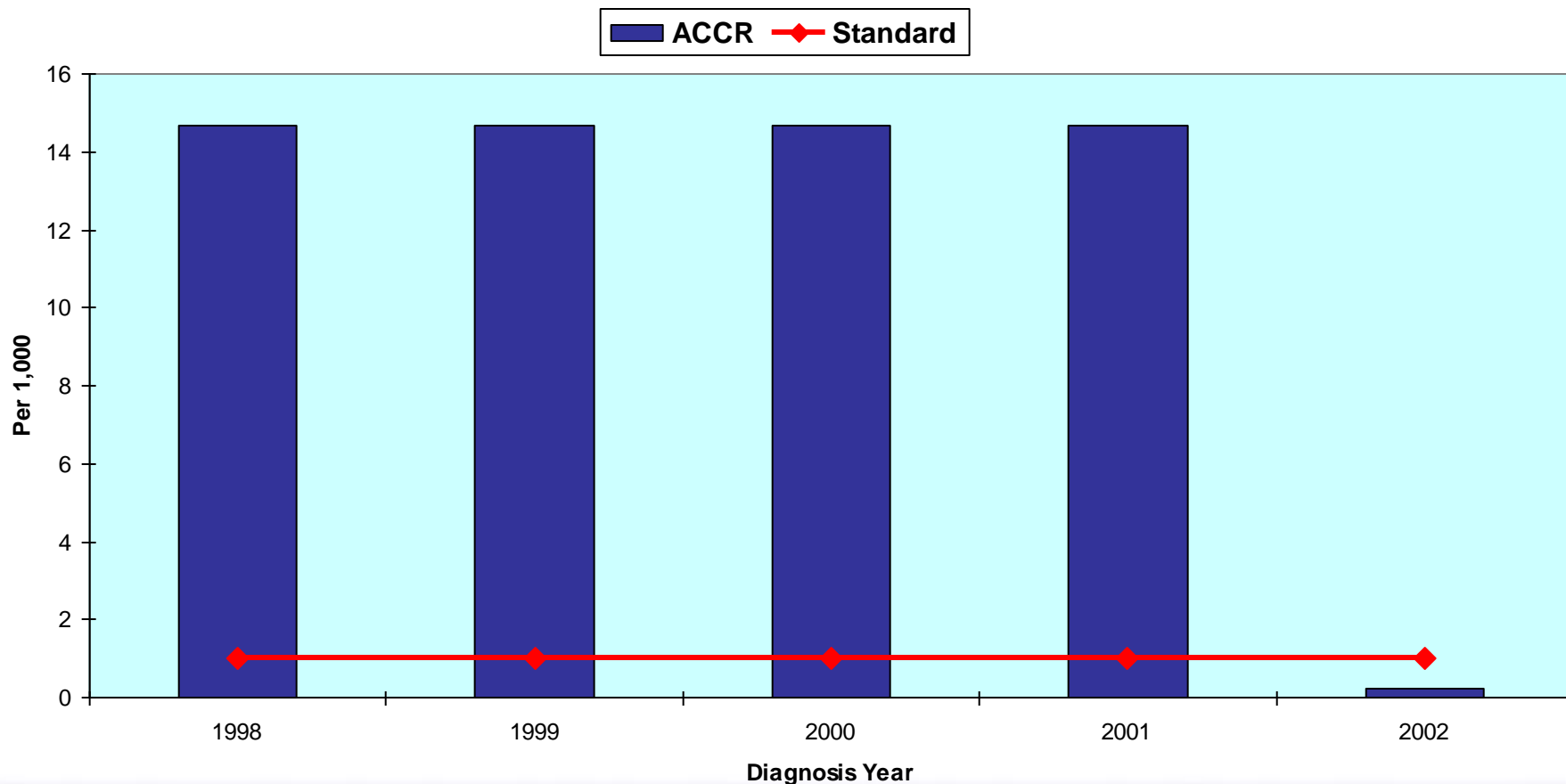
ACCR 2002 Diagnosis Year Case Completeness <95% by Cancer Site

Black Males	Black Females	White Males	White Females
Oral	Esophagus	Oral	Oral
Esophagus	Stomach	Esophagus	Esophagus
Stomach	Colon & Rectum	Colon & Rectum	Colon & Rectum
Colon & Rectum	Liver	Liver	Liver
Liver	Pancreas	Melanoma of Skin	Pancreas
Urinary Bladder	Lung & Bronchus	Urinary Bladder	Melanoma of Skin
Hodgkin Dz	Breast	Brain & Other CNS	Breast
Multiple Myeloma	Cervix	Hodgkin Dz	Cervix
Leukemias	Corpus & Uterus, NOS	Non-Hodgkin Lymphoma	Corpus & Uterus, NOS
	Ovary	Multiple Myeloma	Ovary
	Urinary Bladder	Leukemias	Urinary Bladder
	Brain & Other CNS		Kidney & Renal Pelvis
	Hodgkin Dz		Brain & Other CNS
	Non-Hodgkin Lymphoma		Hodgkin Dz
	Multiple Myeloma		Leukemias
	Leukemias		

ACCR Death Certificate Only Cases



ACCR Unresolved Duplicate Cases



ACCR Strategies for Improvement

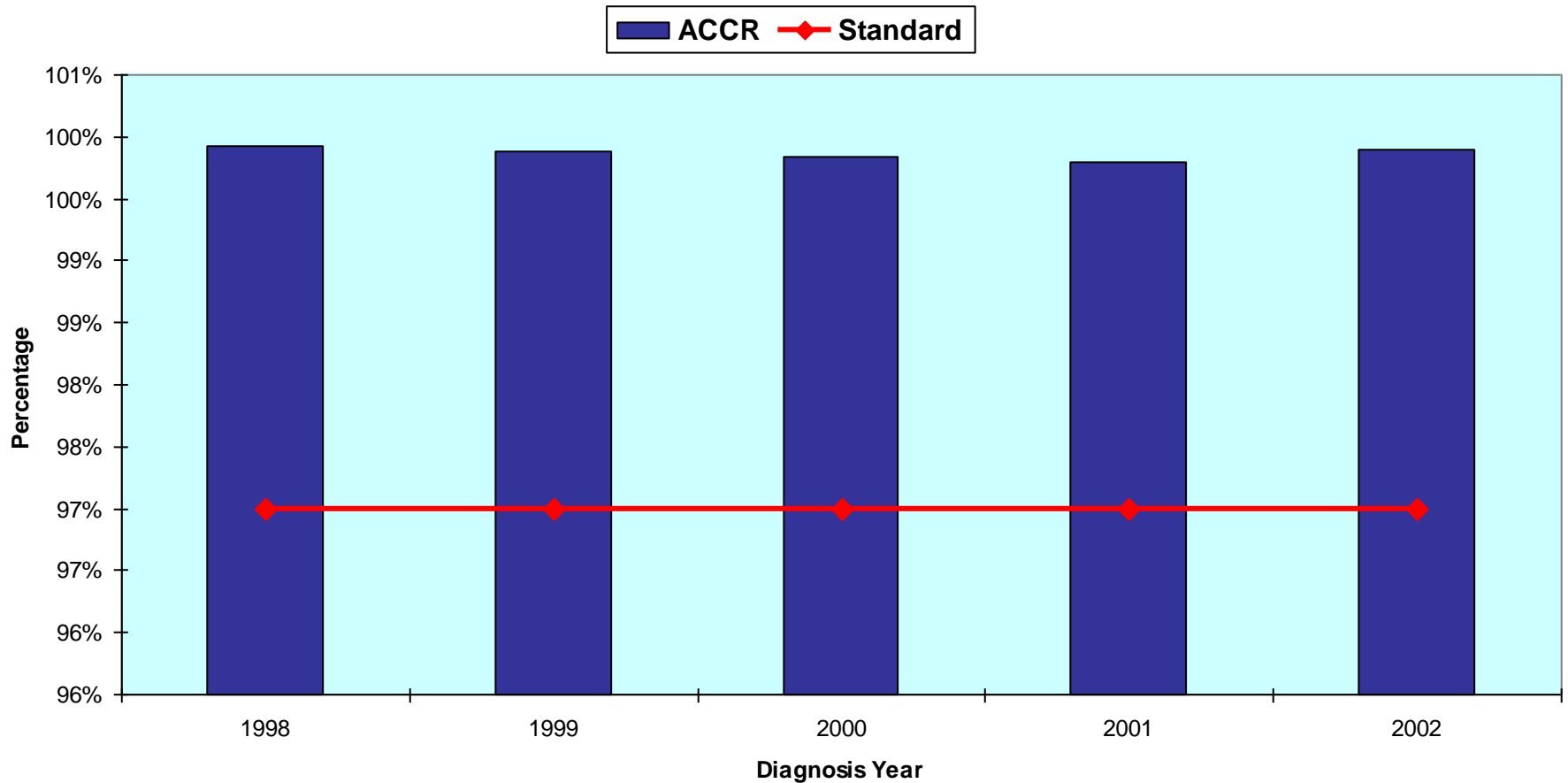
- Completeness related to reporting delay
- Participating in special casefinding audit project
- Increase non-hospital reporting
- Participating in web-based physician reporting project
- Encrypted e-mail or secure web site data submission

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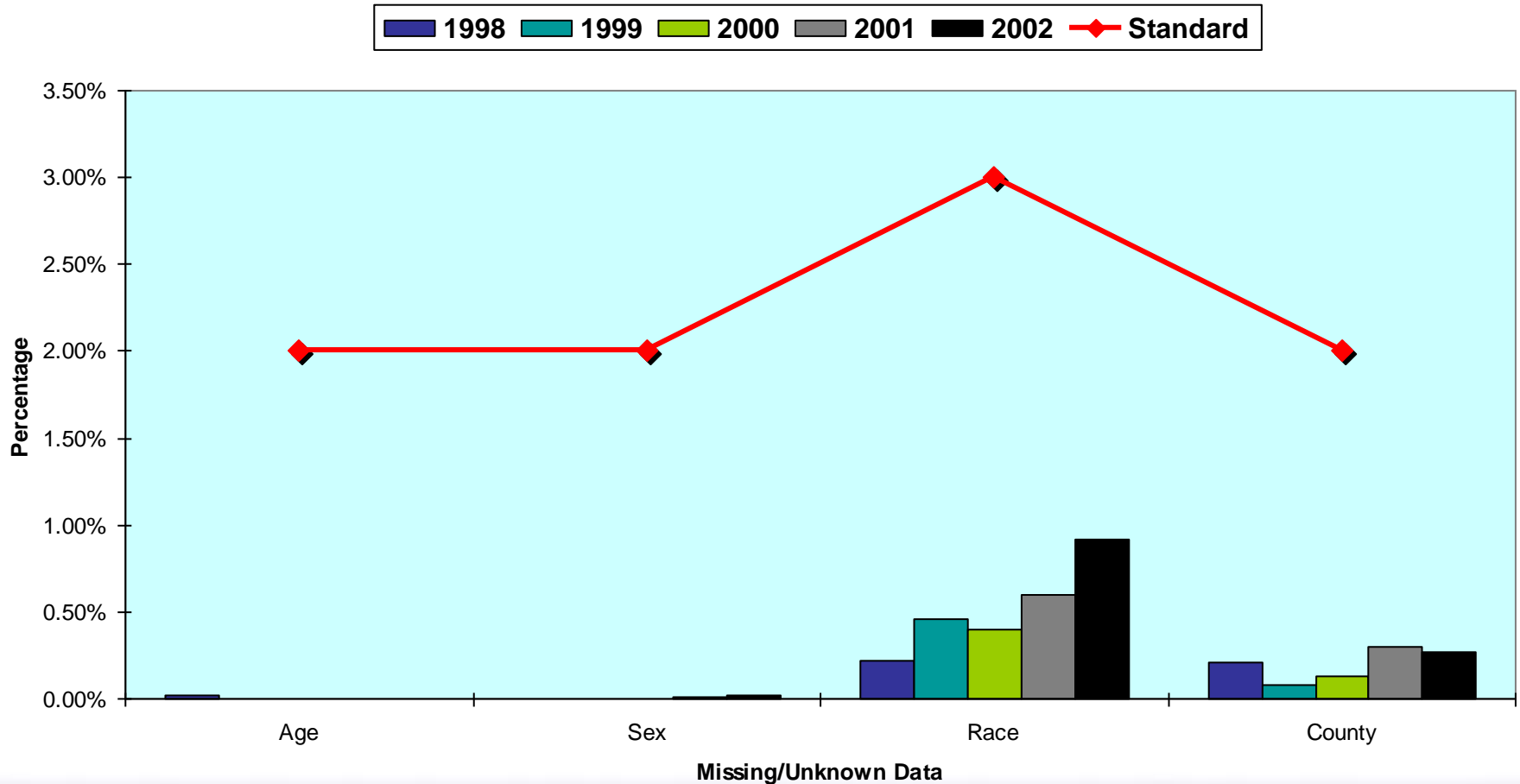
NPCR Program Standards for Data Quality

- Within 12 months of the close of the dx year, 97% of the cases pass an NPCR prescribed set of standard data edits.
- Within 24 months of the close of the dx year, 99% of the cases pass an NPCR prescribed set of standard data edits.
- Funded programs undergo an audit by an independent NPCR approved organization

ACCR Cases Passing Standard Edits



ACCR Data Quality



Challenges in Reporting Race/Ethnicity

- Quality of reporting and coding
 - Census
 - Medical records
 - Cancer registries
 - Death certificates
- Availability of population data

Multiple race/ethnicity categories

NPCR Program Standards for Advanced Activities

- Has conducted at least one advanced activity in past year, such as:
 - Receipt of encrypted case reports
 - Automated casefinding
 - Linkage with NDI for survival analysis
 - Quality of care or clinical studies
 - Publication of research studies using registry data
 - Geocoding to latitude and longitude

ACCR Advanced Activities

- Geocoding activities
- County fact sheets
- Web-based cancer demographics
- Video conference training
- Electronic pathology reporting

NPCR Program Standards for Annual Reports

Effective Diagnosis Year 1996 :

- An accessible and usable analytic database of cancer cases that are at least 90% complete
or
- A report in electronic format based on cancer cases that are at least 90% complete

available by 12 months after the close of the diagnosis year

NPCR Program Standards for Data Use

- In past year, used registry data for planning and evaluation of cancer control in at least 3 ways:
 - Detailed analyses incidence and mortality
 - Linkage w/ statewide cancer screening program
 - Health event investigations
 - Needs assessment
 - Program planning
 - Program evaluation
 - Epidemiologic studies
- Within 24 months, an analytic data set meeting standards for completeness and quality is available for research purposes.

ACCR Annual Report and Data Use

- Web-based query system
- Arkansas County Fact Sheets updated every two years
- ACS Arkansas Facts & Figures
- Cancer concern evaluations
- Identify populations for interventions
- Mapping cancer sites by stage

Using Central Cancer Registry Data

- Surveillance
- Cancer control planning
- Resource allocation
- Research and evaluation
- Linkage to other databases



Demographic Data

- Demographic Information, including at a minimum:
 - Name
 - Address at diagnosis
 - County at diagnosis
 - Race and Spanish/Hispanic origin
 - Sex
 - Birth date
 - Social security number

Clinical Data

- Clinical Information, including at a minimum:
 - Date of diagnosis
 - Date of admission/first contact
 - Source of information
 - Date and type of first course of definitive treatment (surgery)
 - Date of death
 - Underlying cause of death

Pathologic Data

- Pathologic Information, including at a minimum:
 - Primary site
 - Morphology Type, behavior, and grade
 - Sequence number
 - Laterality
 - Diagnostic confirmation

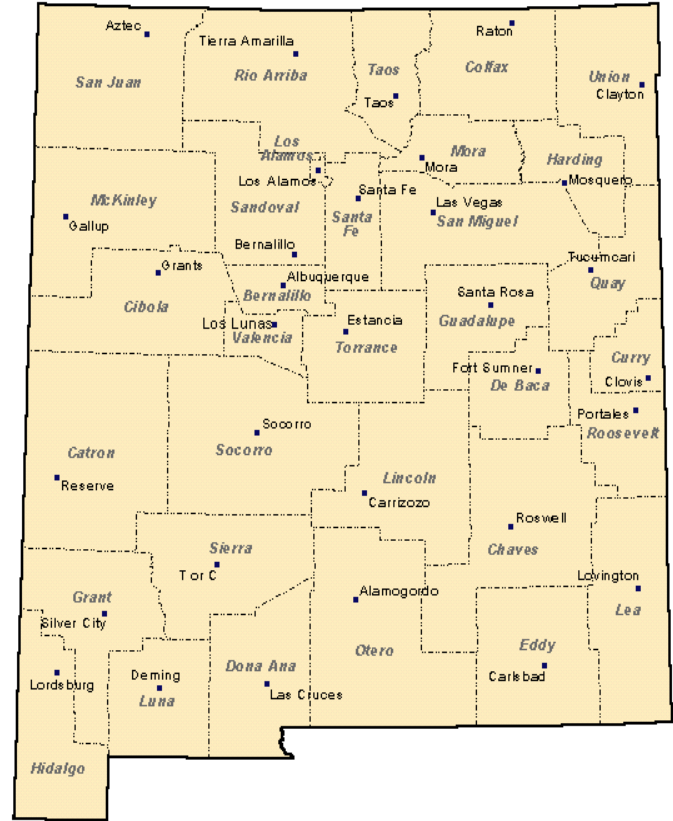
Uses of Registry Data: Evaluation of Policy

Objective: Examine the relationship between age and chemotherapy use

Registry: New Mexico Tumor Registry,
1991-1997

Sites: Breast Cancer

- Identified discrepancy between NIH Consensus Recommendations and community use of adjuvant chemotherapy in women with breast cancer
- **Source:** Xianglin et al., *An. of Internal Medicine*, 2003;138;90-98



Uses of Registry Data: Research

Objective: Examine the association between certain risk factors and high rates of bladder cancer among white adults in Maine, Vermont, and New Hampshire

Registry: Vermont Cancer Registry,
Maine Cancer Registry,
New Hampshire Cancer Registry,

Others: NIH, U.S. Geological Survey, and
Dartmouth Medical School

Uses of Registry Data: Research (*cont'd*)

Methods:

- Case Control Study—1996-2000
 - 1200 adults ages 30-79 (Histologically confirmed bladder cancer)
 - 1200 adults ages 30-79 (no history of bladder cancer)
 - Rapid data collection tools: diet, previous residence, occupation, medical history, and medication and tobacco use
 - Analyzed drinking water and biological specimens

Outcome :

- Provide guidance in the development of public health interventions and education programs to help residents lower their risk for bladder cancer

Patterns of Care Study:

Study Objectives:

- Assess quality/completeness of stage and treatment
- Determine proportion of patients receiving standard of care
- Determine tumor, patient, provider characteristics associated with different treatment patterns
- Treatment outcomes - survival

Colorectal Monograph

Collaboration between CDC, NCI, NAACCR, NPCR registries to use cancer incidence and mortality data to produce a monograph on colorectal cancer in US

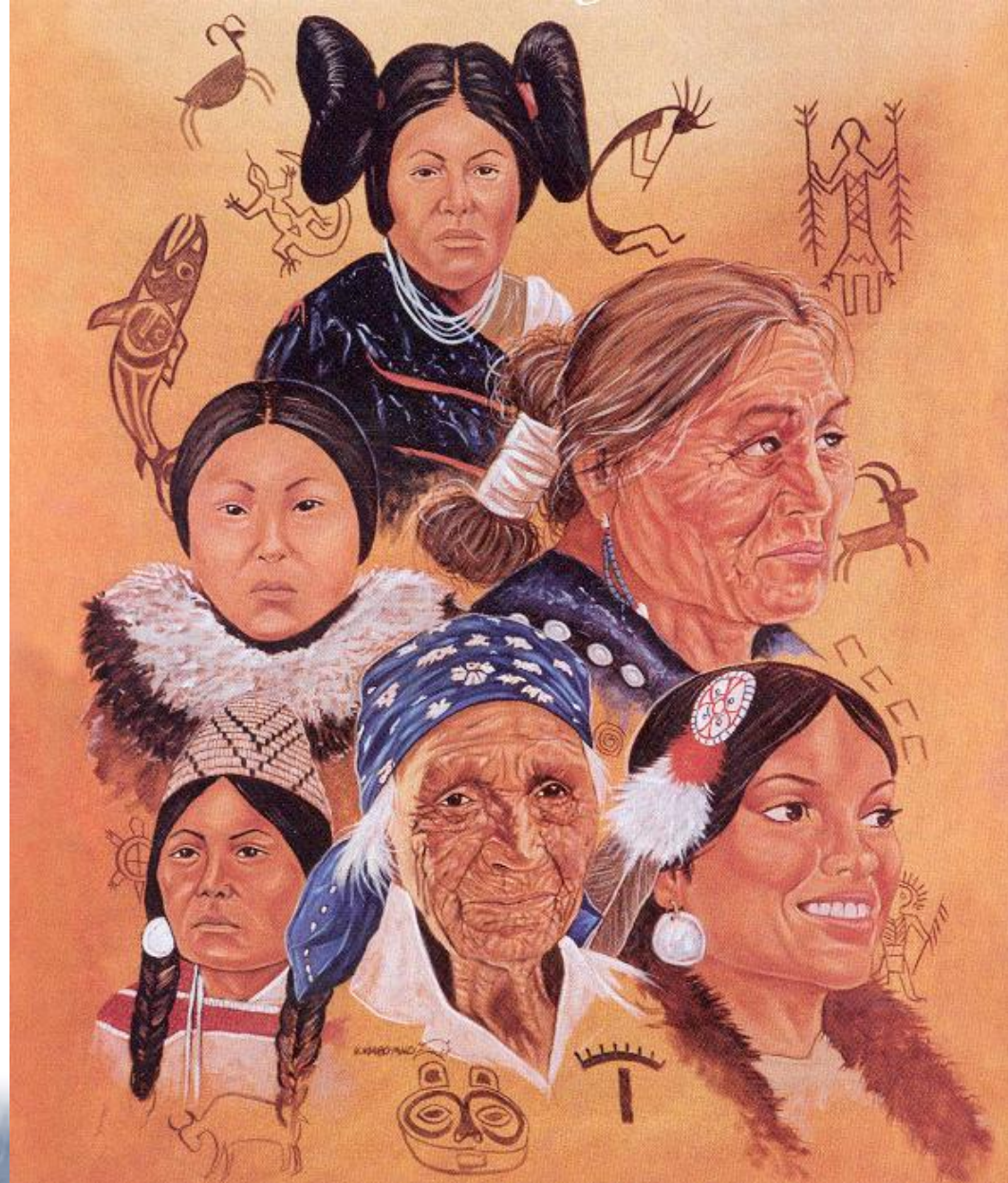
Data analyses objectives:

- Identify groups most at risk for targeted interventions
- Support development of comprehensive approaches to the prevention and control of colorectal cancer

Data Linkage with the Indian Health Service in NPCR

Source: *Native Women's Breast
and Cervical Health*, August 2002

Artist: Virgil "Smoker" Marchand
(Washington State Colville
American Indian)



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• INFECTIOUS DISEASE PROTECTION • PUBLIC PARTNERSHIPS • HEALTHY CHOICES • PREVENTION AND CONTROL

NPCR- IHS Data Linkage Study

- Collaboration with the Indian Health Service
- Goal to improve the classification of American Indian/Alaska Native race in the central registries
- 44 NPCR states and DC submitted data for linkage

Cancer Incidence Rates, 1998-2002

NPCR-IHS Linkage Preliminary Results

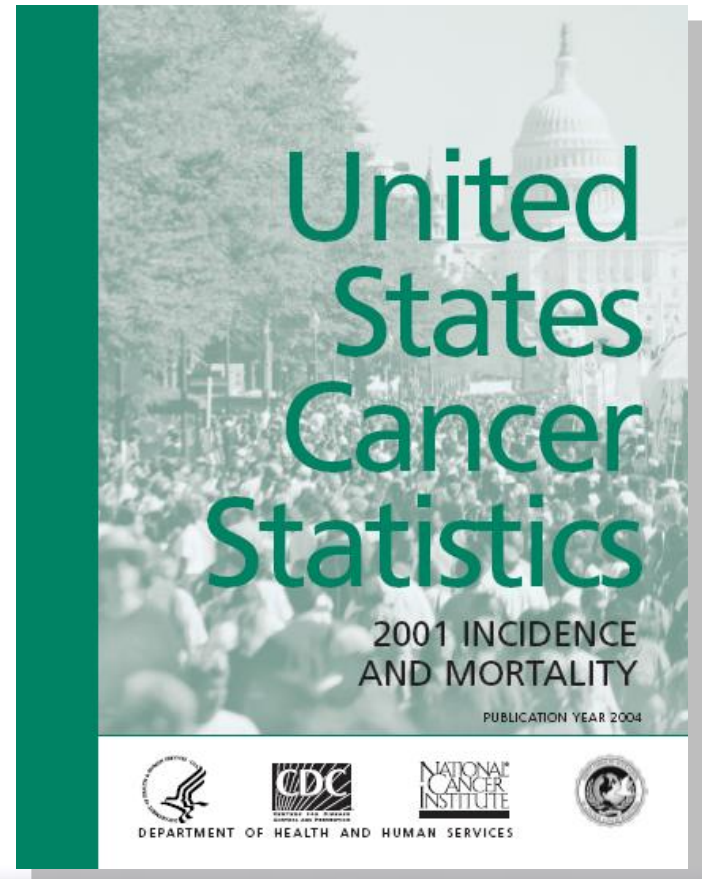
	Before linkage	After linkage
All sites – Male	178.3	227.2
All sites - Female	143.2	188.5
Lung - Male	32.3	40.5
Lung - Female	19.9	27.3
Colon – Male	24.3	29.7
Colon - Female	18.9	24.0
Prostate – Male	42.8	58.5
Breast – Female	37.4	50.5
Rates are per 100,000 persons and are age-adjusted to the 2000 U.S. population.		

Cancer Surveillance System (NPCR-CSS)

- Data aggregation
 - 2001 cases ~ 1.2 million
- Data quality
 - 29 states met NPCR 24 Month Standards

Joint Publication of Cancer Incidence Data

- State, regional, and national data
 - 43 states, 6 metropolitan areas, DC
- 2001 cancer cases
- Rates and 95% confidence limits
- Covers 92% US population



USCS Eligibility Criteria

- Case Ascertainment $\geq 90\%$
- DCO $\leq 5\%$
- Completeness of information:
 - age $\leq 3\%$
 - sex $\leq 3\%$
 - race $\leq 5\%$
- Passing Edits $\geq 97\%$

Web Site

<http://www.cdc.gov/cancer/npcr/uscs/2001/index.htm>

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National Center for Chronic Disease Prevention and Health Promotion

Cancer Prevention and Control

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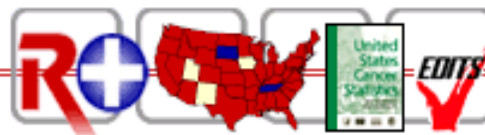
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National Program of Cancer Registries

Data Collection and Surveillance



United States Cancer Statistics

Web-based Incidence and Mortality Reports 1999-2001

On this page

- [2001 Data](#) **NEW!**
- [2000 Data](#) **Updated!**
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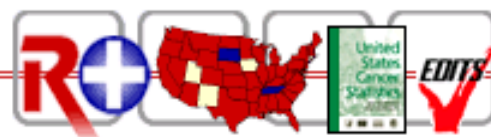
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National Program of Cancer Registries

Data Collection and Surveillance



2001 Incidence and Mortality Data

The Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI), in collaboration with the North American Association of Central Cancer Registries (NAACCR), have combined their data sources to produce official federal statistics on cancer incidence from registries having high quality data. Statistics on death data from CDC's National Vital Statistics System are also included.

See Also

- [About the Report](#)
- [Report Contents](#)
- [Abstract and Citation](#)
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Cancer Data

- [By site and race](#)
- [By age and race](#)

Rankings

- [Top 10 cancers by state](#)
- [By state](#) (PDF-290K)*
- [State vs. national](#) (PDF-1.70M)*

Challenges to Nationwide Cancer Surveillance

- Support and training of hospital registrars
- Reporting from non-hospital facilities
 - cases
 - treatment
- Confidentiality and privacy issues
- Changes in information technology

Ongoing / Future NPCR Initiatives

- Data aggregation - NPCR/CSS
- Technical Assistance/Audits contract
- Education contract
- Data quality studies
- Patterns of care studies
- Linkage studies
- Electronic reporting feasibility studies
- NPCR Program Standards
- Registry certification

Summary

- Now have strong nationwide cancer registry infrastructure in place
- There are population-based cancer registries in all 50 states and the District of Columbia.
- For 2001 cancer diagnoses, we have data for 92% of the U.S. population